DOCUMENT RESUME

ED 298 717 EC 210 751

TITLE Kirsty: The Struggle for a Place in an Ordinary School. CSIE Fact Sheet.
INSTITUTION Centre for Studies on Integration in Education, London (England).
PUB DATE Feb 83
NOTE 5p.; For related document, see ED 292 243.
AVAILABLE FROM Centre for Studies on Integration in Education, 415 Edgware Rd., London, England NW2 6NB (20 pence).
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Adjustment (to Environment); Administrator Attitudes; Admission (School); *Child Advocacy; *Downs Syndrome; Early Childhood Education; Educational Therapy; Foreign Countries; *Mainstreaming; Parent Attitudes; *Parent Participation; Parent School Relationship; Special Education; *Student Placement; Teacher Attitudes
IDENTIFIERS *United Kingdom

ABSTRACT

An account is presented of a 6-year-old British girl with Down Syndrome and the efforts of her parents to have her integrated into a regular school rather than segregate her from "normal" society in a special school. Discussed are: the girl's experience at a playgroup of nonhandicapped children; the attitudes and opinions of the parents and of local education authority personnel; the decision-making process which determined the child's placement in a regular infant school; the school staff's adjustment to integration; and the child's progress in intellectual, social, and behavioral domains. (JDD)

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CSIE FACT SHEET

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SUMMARY

- This case concerns a six-year-old Downs girl, Kirsty, whose parents felt strongly that since their child had experienced a happy integrated pre-school childhood in the local community, the most natural progression once she was of school age, was to send her to the local infants school to continue her integrated life.
- As well as illustrating the fewer rights enjoyed by parents in this situation, and how, unfairly, the onus can be put on to them and their child to succeed, it also demonstrates the crucial importance of a real partnership between parents and the school.
- This FACTSHEET is a brief account of some of the parents' feelings about school for Kirsty, the pressures they faced to send her to a special school and their continuing anxieties and uncertainties for the future, even though they persuaded the local infants school to take her.
- Although integration schemes involving children with physical and sensory handicaps have existed in this authority, Berkshire, for some years, Kirsty in one of the few mentally handicapped children to attend one of the county's ordinary schools.
- Neither the parents, nor the school have been named: anyone wishing to contact them should write to CSIE.

KIRSTY: the struggle for a place in an ordinary school

'There isn't a week that goes by without Kirsty being invited to a party in the neighbourhood. She went to the local integrated pre-school playgroup at the age of three — we looked at several in the area and the closest turned out to be the one we liked the best — and it has been this normal contact with other children and their families, whether in their homes, or here in ours, which has made us feel so sure that pressing for integrated schooling was the right thing to do'.

Kirsty's parents feared there would have been a great upheaval out of the community if they had responded to pressure from the local authority, and the special school in particular, that segregated schooling was the proper kind for their child and not normal schooling somewhere in the neighbourhood. It was not an easy decision to take as Kirsty approached the age of five: she had earlier attended this ESN(S) school once a week for physiotherapy to help get her walking. These ¼ hour sessions stopped at about two when she began walking. Nevertheless, following this first contact with the special school which is three and a half miles away, it was always inferred that Kirsty would go there for both her nursery education and then her full-time schooling from the age of five.

'Over protected'

Her parents felt otherwise. 'The weekly sessions to help get her walking were wonderful, but we saw that the other children were very protected in the special school — it's just the way things are. We're not critical of the school, or that *kind* of school: the staff are extremely dedicated, there's no doubting that. What we *are* critical of is the concept of withdrawing a particular child from its natural environment, its local community, and educating it in a place where children with a variety of handicapping conditions are brought together in a concentration'.

Having the support of the peripatetic home-teacher (home tutor) while trying to secure a place in a local ordinary school where Kirsty's friends from the playgroup naturally progressed on to, was obviously of great help to the parents. But they said that even with this support they felt very much on their own in their pursuit of an integrated setting for Kirsty's schooling: the pressure for Kirsty to take the traditional educational route was 'enormous', and rested on the fact that *no* alternative was ever offered. 'From the word go, all the different people involved in caring for her let us know that they expected an ESN(S) education for Kirsty and nothing more'.

It was an uphill struggle for the parents who soon came to realise they were going against the majority of attitudes and opinions held by individuals as well as those in authority, the most devastating of which was shown early on by a senior hospital doctor soon after Kirsty was born, when the parents were told: 'Don't expect her to live very long: don't look too far into the future as far as your life with Kirsty is concerned'. The local education authority (LEA) also certainly expected her parents to follow the traditional route for children categorised as ESN(S).

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'We were acting from instinct, and still feel we need all the help we can get. For example, diet is extremely important for Downs children and we're trying out a special vitamin booster for Kirsty with the help of the Down's Children's Association and our local doctor, and it seems to be helping at the moment, but we don't know for sure. You often feel you are in the dark over lots of things because the professionals, the education authority and the individual schools all make you feel that they have so much more information and experience than you.'

From the moment she was born Kirsty's parents, who had had no previous experience of disability at all, exposed her to a lot of stimulation, particularly in the first six months and they now feel they have seen clear benefits at various stages of her life. She is a great mimmick, according to her parents, and this has been put to good effect both in playing and learning at home, in the playgroup and in teaching social and behavioural skills in the infants school where she has been for a year and two terms (April 1983).

Her progress in the playgroup, where she mixed easily with all the other children and often helped the smaller ones with various tasks, allowed her to benefit considerably from normal environment. At that time Kirsty was the only handicapped child in the playgroup but they were fully supportive of the parents' wishes for an ordinary education.

Pressure

Thinking back to the pressure they faced to place her in the ESN(S) school, the parents commented: 'Without any malice to the children there, to their parents or to the staff, we could so easily see Kirsty regressing, or staying still in that kind of environment. Putting her in the special school's nursery unit at three years of age definitely wasn't the right thing to do for her at that moment. The playgroup was not a particularly unusual playgroup — which was fine — but it did prove to us what we had felt for a long time, that Kirsty could mix, take part and benefit from remaining in the "normal" community'.

A major factor in this example of integrated education is the clear support for integration shown by the headmistress of the Church of England infants school: without it, Kirsty's parents said they would have probably given in to those pressures. For *her* part, the headmistress said that from the moment she was first approached by the parents and met Kirsty, she was convinced by their arguments as well as their enthusiasm, and she agreed to take Kirsty on a term-to-term basis. 'We have had tremendous support from the parents and we could not have come this far without it: with considerable enthusiasm they have always been involved with the school, they have talked with the staff and carried on with Kirsty's education at home in conjunction with her teacher'.

● *Kirsty*

It was agreed that a case conference at the end of each term would decide whether or not it was working. The ESN(S) school was aware of the arrangements and ready and willing to take Kirsty at a moment's notice if the scheme 'failed': everyone involved knew this as they embarked on the scheme.

The parents said they felt they could not ask for anything more in terms of rights or a guaranteed future for Kirsty, and they described this arrangement for them as being 'on tenterhooks' at times: 'it does highlight the difference in parental rights and security of a school place which parents of ordinary children enjoy compared to that enjoyed by us'.

The headmistress felt that bringing Kirsty into her school was a challenge to everyone concerned: 'If we are not *educating* Kirsty, then we are failing. There is always a place in the special school, so it is up to us to prove it works here'.

Kirsty's parents have observed her in the ordinary infants school and commented: 'She isn't protected from the outside world in that school, and that is just what we wanted. The greater the chance she has in taking part in so-called "normal" society when she grows up, the better. Yes, we have made a direct connection between this ultimate goal of trying to achieve some kind of normality for her when she leaves school, and our seeking an integrated educational setting. We think ordinary schooling makes that goal much more likely than a special school does. She isn't molly-coddled at this school; she has become much more self-reliant; she has to speed up — literally. Downs children tend to be slower and appear to be lazy, but she has adapted and she can keep up with a lot of things in the classroom and elsewhere in the school.

'We are delighted with her progress, which is greater than we had dared hope for, particularly with her reading ability which has also impressed the speech therapist.' The infants school has given her greater independence as well as self-reliance, and this comes out after school and at weekends: for example the regular Saturday morning visit to the adventure playground will see Kirsty moving from one activity to another under her own steam; when she comes home from school she will happily sit down and decide to read to her parents from her *Kathy and Mark* reader for 20 minutes to a half an hour before going upstairs to play on her own in her bedroom for a further half an hour to an hour.

The headmistress said that the strongest benefit to Kirsty in the first year had been a social one. She had not learned 'academic' skills as fast as other children of her own age, but she had gained more by being in the ordinary school, than if she had been in the special school. She added: 'The plus side has been for people already in the school as much as for Kirsty: if it is going to make the ordinary children realise that there are others with greater special needs than themselves, then that alone makes it all worthwhile.

'Kept away'

'I feel that for far too long some children have been kept away from the "ordinary" environment. In Kirsty's case, I will still have doubts until she has learned more concentration and until her spoken language improves. The elder middle infants fussed her when she first came and she lapped it up: even though she could do things herself she let her peers do things for her, and it was something we had to look out for and stop, because it was obviously holding her back'.

Everyone felt the first term was a great success. Kirsty had learned

from the other children who played and chatted to her as much as she did to them, and as they did to each other; she was included in the class group for *all* activities, in spite of the stumbling block of being behind in language development compared with the others. She was also included in all the joint school activities involving other classes.

Those taking part in the first case conference were the headmistress, the class teacher, the support teacher, the home tutor, the area speech therapist, the educational psychologist, and, when this group had finished the bulk of their discussions, Kirsty's parents were brought in. They felt the decision had been made before they went in to the meeting, but of course they were extremely pleased that it went in their favour: Kirsty was to stay another term, by a unanimous decision.

No complaints

The school staff, as well as Kirsty's parents, noticed that other children *made* her say things properly, rather than letting her get away with less than clear words and actions: in her parents' words — 'Some of the best teachers Kirsty could ever have are other children in the ordinary school.' The end of the first term also proved that one anxiety of the head and the parents was quite unfounded — that of complaints from parents of other children in the school: nor have there been complaints or any opposition since then.

The second term — the spring term — was not as good: the headmistress said progress had not been as marked as before, and said she was worried about Kirsty staying in the same class, mainly because the older children wanted to do too much for her and not get on with their own work, or they vied with each other for her attention. It was clear to see how the other children were benefiting and learning after two term's schooling. The other professionals involved in the second case conference were in agreement with the head and it was decided to put Kirsty in the new reception class for the summer term, rather than stay with the group she had come to know and work with.

Kirsty's parents felt they had to go along with the decision, and although they felt that this change might be construed as 'failure', they agreed with the head's advice and the decision of the case conference.

It worked. Kirsty's behaviour according to her parents changed significantly: suddenly she was older than the others, and it was the same as when she was in the playgroup — the new reception class of children were six months younger, and she found *she* could teach them things in the class and around the school, because she had experienced school for eight months more than them. This third term, the summer of 1982, was crucial so far as Kirsty's continued integrated education was concerned — it was the end of the first year and the parents approached the case conference in June with a considerable degree of anxiety.

Things had gone well in the term and included a new dimension of Kirsty joining a small group of six Asian children who were getting half-an-hour's tuition a day on their own from a teacher of English as a second language: in addition Kirsty's mother started taking her to the local welfare clinic for half-an-hour's speech therapy each week, something suggested by the second case conference. This same speech therapist holds frequent sessions in the ESN(S) school and also visits the infants school itself. The term ended with the case conference deciding that Kirsty should continue in September, a decision possibly influenced more than anything else by the head's sincere belief that the school was doing the right thing for Kirsty, that it could cope with her special needs and that it wanted to *educate* Kirsty, rather than simply 'contain' her.

By the new year (January 1983), Kirsty's fifth term in school and at the age of six and a half, her achievements included knowing all her colours and most of her numbers; writing her name with a little help; reading five word sentences from her *Kathy and Mark* reader with ease; a marked improvement in language development; a real understanding of what the teacher was saying; an ability to get herself around the whole of the school competently; a healthy appetite without any problems at school dinner time, and,according to a teacher at the ESN(S) school, much more self-sufficiency than children of a similar age and handicap at the special school. Her ability to concentrate on her own work was improving slowly, and it was decided that this and her language development, which clearly marked her out from the rest of the class, were the areas where most effort was going to be put in future. On a comparitive basis with the rest of the children, Kirsty's parents were told she was 'not bottom of the class in everything': there were one or two others, who at that point in time, had greater problems in some areas.

The head stressed that while her commitment to integration had increased markedly since the scheme had been in operation, she felt she would not let the theory dominate the practice. If she and the staff felt they could not cope or adapt to meet Kirsty's needs, she would recommend that the scheme be ended. At the same time, she agreed that Kirsty's presence in the school implied a lot more than Kirsty simply fitting in with existing structures and curriculum goals. All the staff and some parents of other children had gone through various educational processes and changes in attitude as well as a readjustment of expectations, as a result of Kirsty being in the school; the headmistress added 'While the future might not be certain, nobody — from the director of education downwards — had said we are doing the completely wrong thing. Nothing has happened so far to make me

● *A typical classroom setting for Kirsty.*

think it has been anything but good.'

In her first four terms Kirsty had three different teachers which might have had a slightly unsettling effect, although she has always adapted quickly, once familiar with the teacher. In an effort to understand the problems involved, the head, and all the teachers who had Kirsty, went over to the special school 'to see what a child like Kirsty would be doing in that setting, to see if she was actually missing out on anything, and to see how we could improve the provision we were already making'. Kirsty's arrival at the infants school also lead to some in-service training on special needs for the head and two staff.

In looking to the future the head and other staff are firm about needing extra support, if only part-time, although no formal application had yet gone into the LEA: so far, the class teacher was able to cope with the needs of all the children in the class, but everyone agreed that some degree of regular withdrawal for special tuition would be necessary in the near future; some has already taken place with the headmistress teaching Kirsty on her own.

The ESN(S) school was recently asked if it felt that Kirsty was losing out by not being there: the firm reply to the parents was 'No'. It was true that the pupil-teacher ratios were much better in the special school, but the inter-action in the infants school, as well as the chance to find greater independence in a wider variety of activities, far outweighed the advantages of being in the special school. Other skills such as training and domestic skills could be caught up with in later life.

● *Kirsty at the age of four in the integrated pre-school playgroup*

Kirsty's parents added: 'We're still in the dark about the future, about where Kirsty should go. We have approached one local junior school, but like Kirsty's present school, they too would be breaking new ground, and the head there is not 100 per cent certain that he would take her. He said: "The door is open — there's no objection so long as we can cope with Kirsty's needs". We feel that raises a lot of questions not only about Kirsty's education, but also about the attitude of ordinary schools, so we have to keep a number of options open; one possibility is Kirsty staying on an extra year at the infants school.

'Any parent in the same position as us is going to experience doubts as well as certainties: we both feel very strongly that we're doing the right thing for Kirsty at the moment. You see, we want to give her the greatest possible chance of looking after herself, of living an independent life when we're not around, and to us, the best starting point for that is integrated schooling. After the success of the playgroup and now the local infants school, our hopes and aspirations have grown and changed as we have seen Kirsty thrive and develop from being in those environments'.

February 1983.

Typeset by Planagraphic Typesetters, London SE1 and printed by Contone Ltd., London N11